Some patients or surrogates might believe that a miraculous recovery will occur if their faith is strong enough; insisting on treatments might be a way of demonstrating their faith. Other patients or surrogates might want any intervention that prolongs life, even for a very short time. They might have vitalist religious views that life is a good in itself, regardless of its quality, and that human beings must preserve and prolong life until God determines its end (12).

Physicians need sufficient information about the patient's religious beliefs to understand their impact on specific clinical decisions. Individual beliefs might differ from official doctrines. Furthermore, people who share general beliefs, such as the sacredness of life, might differ in their preferences about specific medical technologies (13). To inquire how religion shapes decisions, a physician might say to Bishop P's daughter, "I know that religion plays an important part in your father's life. I'd like to understand it better. Please help me learn more." Physicians might also need to understand details about the patient's religious beliefs, such as attitudes toward miracles, prayer, and divine intervention (14).

REQUEST FOR INTERVENTIONS THAT CAUSE THE PATIENT SUFFERING

In Case 14.2 the family's request for CPR troubled caregivers, who believed that further interventions were causing pain and mutilation without improving his prognosis. The ethical guideline of nonmaleficence, as well as professional integrity, allows health care workers to refrain from providing interventions that cause significant suffering but prolong the patient's life only briefly (9,15). This rationale justifies overriding surrogate preferences and withholding interventions in rare cases.

Some surrogates state that the patient believes suffering serves a spiritual purpose. Caregivers should examine carefully surrogates' claims about the redemptive nature of suffering. First, the family's views might differ from the patient's. Many patients who believe their illness serves a spiritual purpose will still accept medications for pain and decline burdensome interventions (9). Furthermore, many patients who believe that suffering caused by terminal illness serves some higher purpose choose to forego medical interventions that cause additional suffering but provide limited benefits.

RECOMMENDATIONS

Physicians can respond to requests for life-sustaining interventions in several constructive ways (Table 14-1). The suggestions in Chapter 5 on informed consent might also be helpful.

UNDERSTAND THE PATIENT'S OR SURROGATE'S PERSPECTIVE

When patients or surrogates continue to request life-sustaining interventions that the physician considers inadvisable, the doctor should first try to understand their perspective, including their understanding of the illness, their concerns, their goals, and their expectations for care (16,17). This approach is generally more effective than immediately trying to persuade them about specific

TABLE 14-1

Recommendations for Responding to Requests for Life-Sustaining Interventions

Understand the patient's or surrogate's perpective.
Respond to the patient's or surrogate's needs and emotions.
Be sensitive to ethnic and cultural issues.
Use time constructively.
Find common ground for ongoing care.

clinical decisions such as a Do Not Attempt Resuscitation (DNAR) order (18). Open-ended questions are helpful, such as (18):

- "What concerns you most about your illness?"
- "How is treatment going for you (your family)?"
- "As you think about your illness, what is the best and the worst that might happen?"
- "What has been most difficult about this illness for you?"
- "What are your hopes (your expectations, your fears) for the future?"
- "As you think about the future, what is most important to you (what matters the most to you)?"

Such open-ended questions help elicit patient concerns and emotions (19,20).

RESPOND TO THE PATIENT'S OR SURROGATE'S NEEDS AND EMOTIONS

Empathic comments, which reflect the speaker's emotions, encourage patients or surrogates to explore emotions and to discuss difficult topics (18,21,22). In Case 14.1, when Mr. H has difficulty completing sentences, the physician might say, "It can be frightening to not get enough air." Similarly, in Case 14.2, the physician might say, "Do you feel sad seeing your father so sick?" Some physicians might fear that exploring emotions might arouse in the patient and family feelings of anger, hopelessness, or sadness that doctors are powerless to alleviate. However, patients and families will have these emotional responses whether or not physicians choose to probe them. After these emotions are discussed openly, the patient and family no longer must face them alone. Talking about emotional reactions to serious illness is frequently therapeutic and helps patients and families accept a grave prognosis. Furthermore, anxiety and depression can be treated once they are identified. Patients and families who feel they are understood might be more willing to listen to the physician's perspective.

The physicians can also respond to unrealistic expectations without destroying hope. One approach is to "Hope for the best, and prepare for the worst (23)." Also, physicians can use "wish statements" to align with hopes of the patient or family, while suggesting that the desired outcome is unlikely (24). In Case 14.1 the physician might say, " I wish I could make the odds be in your favor."

BE SENSITIVE TO ETHNIC AND CULTURAL ISSUES

Bishop P and his family were African-Americans. Ethnic factors can be significant in end-of-life care. For example, African-Americans and Hispanic-Americans complete advance directives and wish to forego life support less frequently than other patients (25–27). African-Americans might mistrust physicians and hospitals because of a history of discrimination and limited access to medical care (28).

Rather than leave concerns and suspicions unspoken, physicians might ask specifically about trust. "Many African-Americans worry that they will not receive the care they need. How do you feel about that?" Physicians should also acknowledge that mistrust is an understandable reaction. "I imagine I would feel the same way if I had experienced that." Physicians should not immediately try to reassure the family that all appropriate care will be provided (29). Premature reassurance might deter patients from disclosing their concerns and emotions in enough detail that they can be understood (20).

USE TIME CONSTRUCTIVELY

Patients or surrogates are frequently given bad news in the context of being asked to limit life-sustaining interventions. If possible, they should be given time to absorb the new information before making a decision. However, the passage of time alone might not persuade patients or surrogates to limit interventions. Physicians might suggest a time-limited trial of interventions, with plans to discontinue unless clinically significant improvement occurs. Physicians can also use time to direct attention to palliative care. Doctors might say, "Your father is so seriously ill that it's possible that he might die in the hospital. What would be left undone if he were to die suddenly?" Social workers, chaplains, or the hospital ethics committee can also help the family reach closure.

FIND COMMON GROUND FOR ONGOING CARE

The process of negotiation requires that both sides are willing to compromise (30,31). When patients insist on life-sustaining interventions, a common compromise involves not only adding or increasing interventions but also not withdrawing them (32). Although law and ethics do not distinguish between withholding life support and withdrawing it, the emotional difference might be significant to families.

In almost all cases, physicians can reach an agreement with patients or surrogates on an acceptable plan of care (2,3). In rare instances physicians might conclude, after repeated discussions with them and an ethics committee consultation, that they cannot agree with the patient's or surrogate's request. If the requested interventions are futile in a strict sense or cause significant net suffering to the patient, it is ethically acceptable for the physician to decline to provide them. The patient or surrogate should be notified of this decision and of their right to seek another provider.

PHYSICIAN INSISTENCE ON LIFE-SUSTAINING INTERVENTIONS

Physicians and hospitals might seek to give life-sustaining interventions to an unwilling patient. This section focuses on insistence based on the physician's conscience or religious beliefs.

CASE 14.3 Withdrawal of mechanical ventilation.

William Bartling was a 70-year-old man with chronic obstructive lung disease (33,34). A needle aspirate of a new pulmonary nodule revealed adenocarcinoma. After the procedure he suffered a pneumothorax and required a chest tube and mechanical ventilation. During the next 2 months he could not be weaned from the respirator. Mr. Bartling requested that the respirator be disconnected and signed a living will, a durable power of attorney for health care, and a declaration of his wishes. His family also signed documents releasing the physicians and hospital from liability.

The hospital and physicians refused Mr. Bartling's request, arguing that they had an ethical duty to preserve life and that withholding life-sustaining treatment was incompatible with their born-again Christian pro-life beliefs. Attempts to transfer the patient to another hospital that would comply with his wishes were unsuccessful.

The Bartling case posed the question of whether the caregivers may insist on providing life-sustaining interventions over a patient's refusal. In one survey 60% of attending physicians said they would not withdraw a ventilator from a patient with severe chronic obstructive lung disease who wished it discontinued (35).

ARGUMENTS FOR INSISTENCE BY CAREGIVERS ON INTERVENTIONS

Health care professionals and institutions offer several reasons why their moral or religious beliefs should allow them to impose life-sustaining interventions on unwilling patients.

RESPECT THE AUTONOMY OF CAREGIVERS

Health care professionals are moral agents with values, rights, and consciences. In this view, just as patients have the right to refuse interventions, physicians should also have the right to refuse to violate their professional ethics or personal morality. Because the United States respects freedom of religion, it would be particularly repugnant to require health care workers to carry out actions that violate their religious beliefs. Also, it would be counterproductive to require physicians to act against their moral views. A grudging or antagonistic doctor–patient relationship would not be therapeutic.

RESPECT THE MISSION OF HEALTH CARE INSTITUTIONS

Health care institutions might have a mission statement that expresses their goals and values. Hospices have an explicit philosophy of palliative care. Catholic hospitals have policies that forbid abortions. Many people believe that a pluralistic society should encourage such statements of mission so that patients can seek care at institutions whose moral and spiritual views match their own (36,37).

TABLE 14-2

Objections to Caregivers' Insistence on Life-Sustaining Interventions

Undermining the right of refusal.
Confusion between negative and positive rights.
Lack of timely and clear notification of patients.

OBJECTIONS TO INSISTENCE BY CAREGIVERS ON INTERVENTIONS

Insistence by caregivers on providing interventions over the informed objections of patients is ethically troubling for several reasons (Table 14-2).

UNDERMINING THE RIGHT OF REFUSAL

If caregivers could insist on treatment, the right of competent patients to refuse medical interventions would in effect be nullified. In Case 14.3 the court ruled that the patient's refusal of treatment must be respected: "If the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors (34)."

CONFUSION BETWEEN NEGATIVE AND POSITIVE RIGHTS

Philosophers make a distinction between negative and positive rights. *Negative rights* are claims to be left alone, to be free from unwanted interference or intrusions. An example is the constitutional right to be free of unreasonable searches and seizures. Negative rights might require other people to refrain from intervening, exerting control, or thwarting the person holding the rights. Patients claim the negative right to be free of unwanted medical interventions. To be exercised, this negative right requires physicians to refrain from providing the treatment.

Positive or *affirmative rights*, on the other hand, are claims to receive something or act in a certain way. Positive rights might require others to take action or provide means or resources, not simply to refrain from interfering (38). In Case 14.3 the physicians claimed the positive right to continue medical interventions, even though Mr. Bartling did not want it.

Negative rights are generally considered to carry more moral weight than positive rights (39). Virtually all Western philosophers agree that people have a strong right to be free of unwanted intrusions. This right to be left alone is regarded as fundamental to the idea of a free society. Usually, negative liberty is limited only by promises or role-specific obligations; for example, parents cannot claim a negative right to be freed from providing their children's basic needs. In contrast, positive rights are more difficult to justify and enforce because they generally require other people to do something and because they interfere with the negative rights of others.

LACK OF TIMELY AND CLEAR NOTIFICATION OF PATIENTS

Physicians and nurses who work in a situation in which this conflict is likely to recur should make their position known before taking over care of a patient. Such notification would enable patients to make informed plans for their care and to seek another provider. Similarly, institutions that have policies insisting on certain interventions should notify patients on admission. The burden should be on health care providers to notify patients because they are in a better position to anticipate future scenarios and potential disagreements.

TRANSFERRING CARE OF THE PATIENT

Health care workers should be permitted to withdraw from a case in which they have deep moral objections to the plan of care to be undertaken. However, they also have professional obligations not to abandon patients. Thus, they should allow (and even facilitate) transfer of the patient to a health care worker or an institution that is willing to comply with withdrawal of the intervention.

Some physicians might not want to inform the surrogate of the option of transfer of care because they believe this would constitute cooperation with an immoral act. However, physicians have an obligation to inform patients (or surrogates) of alternatives to the proposed treatment. Generally, even if a physician personally would not carry out a treatment, the physician still needs to mention it if a respected minority of physicians would do so. The obligation would be even stronger if the intervention were generally considered an acceptable option. If the physician did not want to provide the information personally, he or she could ask another physician or the ethics committee to do so.

Even when transfer of care can be arranged, it might place a heavy burden on patients or their families. Patients might face a tragic choice if they must either accept unwanted interventions or else leave caregivers with whom they have developed a long-term relationship. An example is the Requena case, in which a 57-year-old woman with amyotrophic lateral sclerosis wanted tube feedings withheld if she could no longer swallow. The hospital asserted that her decision conflicted with its pro-life values and asked her to accept transfer to another local hospital that would respect her decision. When she refused to accept the transfer, the hospital went to court to force her to leave. According to the court, because she had lived in the hospital for 17 months transfer would be upsetting and burdensome for her. The trial court judge suggested that "by rethinking their own attitudes" the hospital staff "might find it possible to be more fully accepting and supportive of Ms. Requena's decision." The court continued, "It is fairer to ask the health care workers to bend than to ask Ms. Requena to bend (40)."

In summary, the claims of health care professionals to insist on interventions might negate the rights of competent, informed patients to refuse them. Caregivers should not expect to impose treatment on patients if they did not notify them of their insistence when care was initiated.

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SECTION III

Decisions about Life-Sustaining Interventions

CHAPTER 15

Confusing Ethical Distinctions

In discussions about life-sustaining interventions, physicians often draw distinctions that seem intuitively plausible but prove problematic on closer analysis. Examples are distinctions between withdrawing and withholding interventions and between extraordinary (or heroic) and ordinary care. On the other hand, some ethical distinctions, although less intuitive, are nonetheless ethically valid. In particular, physicians might not understand the important distinction between providing very high doses of opioids to relieve symptoms and intentionally administering opioids to kill the patient (1). Physicians need to appreciate which distinctions are ethically meaningful and which are not because failure to do so often leads to confusion and poor care.

CASE 15.1 Withdrawal of mechanical ventilation.

Mr. C, a 68-year-old man with severe chronic obstructive lung disease, developed respiratory failure after an episode of bronchitis. He had told his outpatient physician repeatedly that he was willing to be on a ventilator in the intensive care unit, but only for a brief period. If he did not recover, he wanted the physicians to let him die in peace. After 2 weeks on antibiotics, bronchodilators, and mechanical ventilation, Mr. C showed little improvement and was still in respiratory failure. He asked his physicians to discontinue the ventilator and to keep him comfortable while he died. His family and primary physician believed that his decision was informed.

Some health care workers objected to discontinuing the ventilator. They argued that although the patient may refuse life-sustaining interventions, removing them would be tantamount to murder. Other health care workers believed that it would be appropriate to discontinue heroic treatments such as the mechanical ventilation but that ordinary treatments such as antibiotics and intravenous fluids needed to be continued. Still others objected to the use of sedating doses of opioids for the relief of dyspnea after the ventilator was withdrawn because they would hasten death.

WITHDRAWING AND WITHHOLDING INTERVENTIONS

Many physicians and nurses are willing to withhold interventions but reluctant to withdraw them once they have been started. In one survey 82% of attending physicians were willing to withhold mechanical ventilation from a patient with severe chronic obstructive lung disease who refused it but only 59% were willing to withdraw the ventilator in such a situation (2). In a more recent study only 78% of physicians and 57% of pediatric intensive care unit (PICU) nurses agreed that withholding and withdrawing are ethically the same (3).

This distinction seems plausible because discontinuing the ventilator is frequently characterized as a positive action, but not starting the ventilator might seem more passive and therefore less reprehensible. In everyday life, people generally are held more responsible for their actions than for their omissions. This distinction between acting and refraining from action, however, is not tenable in clinical medicine. Philosophers have devised ingenious examples to illustrate how the distinction between acting and refraining from acting cannot, by itself, be decisive (4). Suppose that the ventilator is accidentally disconnected from the patient. It is problematic to argue that it was permissible to refrain from reconnecting the ventilator but not to take action to disconnect it. In either situation the physician has an ethical obligation to respect the patient's preferences and to act in the patient's best interests. If the patient wishes the ventilator continued and the physician does not reconnect it, it is morally wrong, even though the physician might be said to withhold the ventilator or refrain from acting. Conversely, if a patient wishes to discontinue mechanical ventilation, as in Case 15.1, respecting the patient's wishes requires the physician to withdraw it. The distinction between withdrawing and withholding is not decisive; the patient's preferences are. The considerations that justify not initiating a treatment—in Case 15.1 informed refusal by a competent patient—also justify discontinuing it.

In many cases justifications for withdrawing treatment are more powerful than reasons to not initiate it. Additional information might become known after treatment has started—for example, that the patient did not want treatment or has end-stage disease. Furthermore, a hoped-for benefit might not materialize, as shown in Case 15.1 (5). Typically decisions on life-sustaining treatment must be made when the patient's prognosis is still uncertain. A time-limited trial of intensive therapy might be appropriate in this situation (6). If a treatment proves ineffective, there is no point in continuing it. However, if people were unable to discontinue a treatment once it was started, they might not even try interventions that might prove beneficial (7).

The courts have consistently ruled that there is no distinction between discontinuing medical interventions and not initiating them (8,9). In this book we use the term "forego" to include both withholding and withdrawing interventions (5).

EXTRAORDINARY OR HEROIC CARE

People might intuitively distinguish between extraordinary and ordinary care. Interventions that are highly technological, invasive, complicated, expensive, or unusual are sometimes regarded as "heroic" or "extraordinary." Examples are mechanical ventilation and renal dialysis. In contrast, antibiotics, intravenous fluids, and tube feedings are typically considered "ordinary" care. Some ordinary measures are commonly considered basic care or a standard nursing measure, such as a warm, dry bed. Often, it is argued that extraordinary treatments may be withheld or withdrawn, but not ordinary ones. In one survey 74% of doctors and nurses found this distinction helpful in making decisions (10).

This distinction, however, is not logical and is not a reliable guide to decisions (5). It is indeed appropriate to withdraw mechanical ventilation from Mr. C in Case 15.1. However, the reason is not that the ventilator can be characterized as extraordinary or heroic but rather that it provides little benefit and the patient does not want it. Instead of trying to determine whether the technology should be considered extraordinary or ordinary, physicians should examine the benefits and burdens of the intervention in the particular case, as well as the patient's preferences. In other clinical settings, such as during general anesthesia for surgery, mechanical ventilation is highly effective, desired by patients, and universally used. More important, the benefits of the intervention far outweigh the burdens in Case 15.1. Similarly, physicians need to encourage patients or their surrogates to assess the benefits and burdens of interventions rather than try to classify the interventions as heroic or ordinary.

The courts have rejected distinctions between ordinary and extraordinary interventions (8,9). Numerous rulings have declared that interventions ranging from ventilators to tube feedings may be withheld or withdrawn in appropriate circumstances. Chapter 20 discusses tube feedings in more detail.

RELIEVING SYMPTOMS WITH HIGH DOSES OF OPIOIDS AND SEDATIVES

Relief of pain and other symptoms in terminal illness, such as shortness of breath, is often inadequate. In the SUPPORT study of seriously ill patients, 50% of patients who died experienced moderate to severe pain in their last 3 days of life (11). Doctors might be reluctant to prescribe opioids in sufficient doses to relieve symptoms, or nurses might be reluctant to administer them (12). Some health care workers withhold opioids because they fear patients will become addicted. However, addiction rarely develops in terminal illness and should not be a primary consideration under these circumstances. Another concern is that the dose of opioids required to relieve symptoms might hasten the patient's death by suppressing respiration or causing hypotension. The doctrine of double effect, long-standing in moral philosophy, addresses this concern.

THE DOCTRINE OF DOUBLE EFFECT

Like all interventions, opioids and sedatives have both intended effects and unintended side effects. The doctrine of double effect distinguishes effects that are intended from those that are foreseen but unintended (13–16). In this view intentionally causing death is wrong. However, physicians may provide high doses of opioids and sedatives to relieve suffering, provided that they do not intend the patient's death. Such high doses are permitted even if the risk of hastening death is foreseen. The double effect doctrine also requires that the bad effect (the patient's death) not be the means to accomplish the good effect (relief of suffering). In addition, the unintended but foreseen bad effect must be proportional to the intended good effect. For example, it would be inappropriate to begin treatment of mild pain with very large doses of opioids. However, if the patient's suffering is greater, the physician can justify a greater risk of potentially contributing to the patient's death.

PROBLEMS WITH THE DOUBLE EFFECT DOCTRINE

The doctrine of double effect is widely accepted in this context of high doses of opioids and sedatives to relieve pain. One survey found that almost 90% of physicians and nurses agreed that it is appropriate to administer medication to relieve pain even if the medication hastens a patient's death (10). The Supreme Court has accepted the doctrine (*see* Chapter 22).

However, the doctrine presents several problems (13,17). First, it presents a questionable account of intention (13,18). Physicians might have multiple intentions (19). In one study physicians who ordered sedatives and analgesics while withholding life-sustaining interventions said they intended both to decrease pain and to hasten death in about a third of cases (20). Second, the doctrine of double effect seems to focus on how physicians articulate their intentions. The doctrine of double effect seems to imply that physicians are more justified in administering large doses of opioids if they can put out of mind the possibility that death might be hastened. Third, people generally are held accountable for consequences they foresee or should have foreseen, not merely for those consequences that they intended (5). Thus, the doctrine of double effect might be inconsistent with widely held ideas about responsibility for actions.

The issue of intention is further clouded because refusal of medical interventions by a competent patient might involve the intention to hasten death in some cases. Many competent patients who forego life-sustaining interventions do not want to continue a particular treatment but hope nevertheless that they can live without it. However, some patients who refuse life support intend to bring about their death. There is broad agreement that physicians should respect patient refusals of interventions, even when the patient's intention is to die. Thus, although intention is central to the doctrine of double effect, it should not be the only criterion for judging an action right or wrong.

Despite problems with the doctrine of double effect, it is well established that it is acceptable to use opioids to relieve pain and other symptoms, even if it hastens the patient's death. Because of controversies surrounding the doctrine of double effect, it might be helpful to give an alternative justification for high doses of opioids and sedatives to relieve refractory symptoms. When terminally ill patients experience refractory symptoms, the physician is caught between two duties: to

relieve suffering and not to cause the patient's death. In balancing these conflicting duties, proportionality is important. The risk of hastening death is warranted if lower doses have failed to relieve the symptoms (5). In this situation it is more important to relieve refractory symptoms than to prolong a painful existence for a few hours or days.

PRACTICAL ASPECTS OF RELIEVING REFRACTORY SYMPTOMS

Intention is judged by a person's actions, as well as by his or her statements. Physicians cannot simply say that they intended to relieve pain; their actions must also be consistent with their statements (1). What approach to the use of opioids and sedatives is consistent with an intent to relieve pain but not to hasten death?

If the physician's intent is to palliate symptoms, his or her actions must allow the possibility for symptoms to be relieved without hastening death. The initial dose should not be expected to suppress respiration or cause hypotension. A lethal dose allows no possibility that the patient would survive and would constitute active euthanasia.

If the physician intends only to palliate suffering, there is no warrant for increasing the morphine dose when the patient is comfortable. In conscious patients the dose can be increased if the patient reports unacceptable symptoms. If patients are unconscious or otherwise unable to report pain, physicians and nurses must assess whether patients are comfortable. The dosage should be increased if the patient is restless or grimaces, withdraws from stimuli, or has hypertension, tachycardia, tachypnea, or any other findings that could reasonably be interpreted as suffering. Increasing sedation in the absence of such signs of distress would imply that the physician intended to hasten death and would cross the line from palliative care to active euthanasia (1).

RESPONSES TO REFRACTORY SUFFERING

Some terminally ill patients might experience suffering that even excellent palliative care and high-dose opioids do not relieve. Examples are uncontrollable pain, dyspnea, bleeding, and inability to swallow oral secretions. How should physicians respond in such dire situations? They have other options such as terminal sedation and voluntarily stopping of eating and drinking (13). Unlike physician-assisted suicide and active euthanasia, these practices are legal in all states.

TERMINAL SEDATION

Terminal sedation goes beyond high-dose opioids in several ways. The patient is sedated to unconsciousness in order to control symptoms, usually through administration of barbiturates or benzodiazepines. In addition, all life-sustaining interventions are withheld. The patient then dies of dehydration, starvation, or some other intervening complication. Although death is inevitable, it is delayed for a few hours to over 7 days, depending on clinical circumstances.

Although widely accepted, terminal sedation is not free of controversy (13). Terminal sedation is sometimes done without the express agreement of patients or surrogates or without explicit discussion that other interventions will be withheld (21). Such cases are problematic. In withholding life-sustaining interventions while a patient is terminally sedated, doctors claim that they are not killing the patient but simply respecting the patient's or surrogate's refusal of interventions. This claim is ethically acceptable only if the patient or surrogate has consented to foregoing these interventions. In addition, there might be confusion about the physician's intention and responsibility. It seems implausible to claim that death is unintended when a patient who wants to die is sedated to unconsciousness, life-sustaining interventions and artificial nutrition are withheld, and death is certain. Although sedation is intended to relieve the patient's suffering, the additional step of withholding fluids and nutrition is needed not to relieve pain but to hasten the patient's wished-for death. Furthermore, the notion that terminal sedation is merely "letting nature take its course" is unconvincing because often the patient dies from the withholding of nutrition and fluids, not of the underlying disease. Some writers argue that terminal sedation cannot be meaningfully distinguished from active euthanasia (22).

Terminal sedation also has limitations as a response to refractory suffering. First, some patients find terminal sedation unacceptable because prolonged unconsciousness before death violates their dignity or causes their families to suffer. Patients who wish to die in their own homes might not be able to arrange terminal sedation at home. Second, terminal sedation cannot relieve some symptoms, such as

uncontrollable bleeding or inability to swallow secretions. Although patients are not conscious of these conditions once they are sedated, their death cannot be considered dignified or peaceful.

Despite these concerns, terminal sedation is both ethically and legally acceptable. Doctors can ensure that terminal sedation is appropriate. Physicians should check that the patient has received excellent palliative care, that the decision to carry out terminal sedation is informed and voluntary, and that the patient does not have major depression.

VOLUNTARY STOPPING OF EATING AND DRINKING

When voluntarily stopping eating and drinking, the patient decides to discontinue oral intake and is "allowed to die," primarily of dehydration or some intervening complication (13). Ethically and legally, the right of competent, informed patients to refuse life-prolonging interventions is firmly established. Forcibly feeding a competent patient who refuses food and fluids would violate the patient's autonomy. Because stopping eating and drinking requires considerable patient resolve, the voluntary nature of the action is clear. Stopping eating and drinking might seem natural because severe anorexia commonly occurs in the final stage of many illnesses.

The main disadvantage is that voluntary stopping of eating and drinking requires considerable resolve. The process might last for up to 2 weeks and therefore might seem inhumane. Initially, the patient might experience thirst and hunger. Ice chips and mouth care usually relieve discomfort, and pain medication might also be needed. Subtle coercion might occur if patients are not regularly offered the opportunity to eat and drink, yet such offers might be viewed as undermining the patient's resolve. Patients are likely to lose mental clarity toward the end of this process, which might raise questions about voluntariness or seem unacceptable to some patients or families.

EMOTIONAL REACTIONS TO THESE DISTINCTIONS

Physicians need to appreciate that these topics raise emotional as well as philosophical issues. To many people stopping a treatment is much more difficult emotionally than not starting it. Health care workers might feel that they are causing the patient's death by withdrawing a ventilator, discontinuing vasopressors, turning off a pacemaker or an automatic implantable cardiac defibrillator, or administering large doses of opioids or sedatives. The shorter the time between the withdrawal of the intervention and the patient's death, the more responsible the health care worker might feel for killing the patient. Such feelings might be particularly strong in nurses who are asked to actually disconnect the ventilator or to turn down the settings (23).

Doctors should routinely elicit the concerns, feelings, and objections of other health care workers as well as patients or surrogates about these issues. Moreover, doctors need to acknowledge the depth and sincerity of such feelings. Team meetings and family meetings are often helpful for this purpose. Similarly, physicians need to ascertain whether the patient or family has reservations about the plan of care.

Strong emotional reactions, such as a pang of conscience, might be a clue that further deliberation and discussion are needed. However, health care workers should try to articulate the reasons for their emotional reactions. The fact that something is emotionally difficult does not necessarily mean that it is unethical. In Case 15.1 the attending physician needs to explain that ethically and legally, the cause of Mr. C's death is considered to be his chronic obstructive pulmonary disease, not the discontinuation of mechanical ventilation. Supporting this ethical position, the law clearly states that discontinuing treatment is not murder or suicide (8,24).

The concerns of nurses and house staff should be accommodated if reasonably possible. Nurses who have strong personal objections to the plan of care should not be required to carry it out if other arrangements can be made to care for the patient. Generally, other nurses will volunteer to care for the patient. The attending physician should closely monitor the administration of opioids and sedatives rather than leave it to the nurses and house staff. Nurses and house officers appreciate it when the attending physician is at the bedside when mechanical ventilation is withdrawn.

In summary, several commonly held distinctions regarding life-sustaining interventions are not logically tenable. Physicians should appreciate that it might be appropriate to withdraw interventions that have been started or that some persons consider ordinary care. In addition, administering high doses of opioids and sedatives is appropriate to relieve symptoms in patients who have terminal illness or who have refused mechanical ventilation.

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CHAPTER 16

Ethics Committees and Case Consultations

Ethical dilemmas in clinical practice can lead to deep disagreements and strong emotions. The Joint Commission on Accreditation of Healthcare Organizations requires institutions to have a mechanism to address ethical issues in patient care, such as an ethics committee or a consultation service. Ethics case consultations might be carried out by the full ethics committee, by a smaller team, or by an individual consultant; we thus use the term "ethics consultant" to refer to a group or to an individual. Compared to court proceedings, such consultations are timelier, less adversarial, and more flexible. This chapter reviews the goals, problems, and effective procedures of ethics consultations. Although ethics committees usually have several tasks, such as educational activities and development of institutional policies, this chapter focuses only on their work as consultants.

GOALS OF ETHICS CONSULTATIONS

The goal of ethics consultations is to help resolve uncertainty and disagreements over ethical issues in clinical care. Ethics consultations in intensive care unit (ICU) cases involving value conflicts reduce the length of hospitalization for patients who die during the hospitalization and are viewed as helpful by family members (1,2).

CASE 16.1 Disagreement between family and health care team.

A 76-year-old widower with severe Alzheimer disease is cared for by his two daughters and their families. He does not engage in conversations but usually responds appropriately to simple questions. He often smiles when playing with his grandchildren and when watching television. For the third time in 6 months, he is hospitalized for aspiration pneumonia.

The physicians believe that antibiotics are "futile" in this case and strongly recommend a palliative approach. The patient has not appointed a health care proxy but had indicated to his primary physician that his daughters should make decisions for him. His daughters acknowledge that their father has limited life expectancy but believe that he still has acceptable quality of life. "His family was always the most important thing to him. He always said that nothing made him happier than seeing his grandchildren grow up."

CLARIFY THE FACTS OF THE CASE

The first step in ethics case consultations is to gather information about the medical situation and the ethical issues in the case. Ethics committees or consultants should not uncritically accept second-hand data, which might omit important information or views (3,4). Moreover, important information

might be omitted or conclusions and inferences presented rather than primary data. For instance, physicians or nurses might describe interventions as "futile" without explaining in what sense they are using this term. In Case 16.1 several clinical issues also need to be clarified, such as the patient's baseline functioning, the effectiveness of mechanical ventilation for treating respiratory failure in this setting, and the risk of recurrent aspiration if the patient recovers. In addition, the ethics consultants need to gather information relevant to the key ethical issues, such as previous statements by the patient about his wishes for care.

IDENTIFY AND ANALYZE UNCERTAINTY AND CONFLICT OVER ETHICAL ISSUES

Physicians, patients, and families commonly use ethical concepts and terms without analyzing them carefully. In Case 16.1 concepts needing clarification are futility (*see* Chapter 9), quality of life (*see* Chapter 4), surrogate decision-making (*see* Chapter 13), and the distinction between ordinary and heroic interventions (*see* Chapter 14). However, although an analysis of ethical issues is essential, few dilemmas in clinical ethics are resolved solely by philosophical analysis.

BUILD CONSENSUS AMONG STAKEHOLDERS

Ethics case consultants should help the stakeholders arrive at decisions that are acceptable to them and that fall within the bounds of acceptable ethical practice (5). Ethics consultants should not impose their own personal views about the course of action but rather allow the stakeholders to reach a decision that is consistent with ethical guidelines, their own values, and the patient's values. This process usually requires discussion and negotiation (Table 16-1).

Help Stakeholders Express Their Views and Concerns

Patients and family members often feel that physicians are not listening to them. Conversely, physicians often complain that patients and family members do not hear their recommendations.

Ethics consultants need to elicit the concerns and views of the various stakeholders. When patients and relatives feel their voices have been heard, they usually are more willing to listen to the physicians' assessment of the patient's prognosis and to recommendations. Moreover, physicians who hear the patient and family generally appreciate that their positions are based on deeply felt concerns, needs, and values. The ethics consultant can facilitate such communication through active listening skills and summarizing each stakeholder's perspective.

Provide Emotional Support

In situations such as the one discussed in Case 16.1, emotions often are intense. In response to the patient's serious clinical situation, the children might have a variety of feelings, including grief, anxiety, and anger.

The attending physician, house officers, and nurses in Case 16.1 felt frustrated that they could not resolve the conflict. Unless such feelings are explicitly expressed and acknowledged, discussion

TABLE 16-1

Goals of Ethics Case Consultations

Clarify the facts of the case.
Identify and analyze uncertainty and conflict over ethical issues.
Build consensus among stakeholders.
Help stakeholders express their views and concerns.
Provide emotional support.
Negotiate an acceptable resolution.

of substantive issues is unlikely to be fruitful. Thus, an ethics consultant needs to communicate respect and empathy to all parties.

Negotiate an Acceptable Resolution

Ethics consultants need to know how to lead a discussion, to assure that all views are presented, and to help parties appreciate other points of view (6). Formal bioethics programs rarely teach these interpersonal skills. Parties who originally were in conflict are willing to go along with the final plan, even if it is not the approach they would take personally. Even if their view does not prevail, health care workers, patients, or surrogates might feel that their concerns have been addressed and are therefore more willing to accept the final decision.

POTENTIAL PROBLEMS WITH ETHICS CASE CONSULTATIONS

Although ethics consultations might help resolve disputes, they might also be problematic (Table 16-2) (3,7), as the following continuation of Case 16.1 illustrates.

CASE 16.1 Continued.

At the attending physician's request, two members of the ethics committee review the medical record. They agree that antibiotics are futile in this situation. Family members are outraged. "Who are these people? They never even spoke to us."

LACK OF PARTICIPATION OF PATIENTS OR SURROGATES

Patients or relatives usually feel outraged if ethical issues are resolved "behind closed doors" without their knowledge or participation and by people whom they have never met (3). They might feel that their decision-making responsibility has been usurped. In several well-publicized cases, ethics consultations were criticized for failing to allow surrogates of incompetent patients to participate in discussions (7).

BIAS OR PERCEIVED BIAS

Patients or surrogates who disagree with physicians might regard an ethics consultation as serving the interests of physician or institution. Ethics consultants are generally employees of the hospital and might be colleagues of the health care workers in the case. Hence, families might perceive them as siding with the interests of the doctors, nurses, and hospital.

UNSOUND RECOMMENDATIONS

Agreement among ethics committee members or consultants does not guarantee that their recommendations are sound. In Case 16.1 the ethics committee members adopted a view of "futility" that is highly problematic (*see* Chapter 9). Antibiotics are effective in treating the episode of aspiration pneumonia, but they have no impact on the course of dementia or the risk of further episodes of aspiration. Unsound thinking by the ethics consultation team might result from lack of knowledge,

TABLE 16-2

Potential Problems with Ethics Consultations

Lack of participation of patients or surrogates.
Bias or perceived bias.
Unsound recommendations.
Problems beyond the scope of an ethics consultation.

unrecognized bias, or flawed committee procedures. One empirical study found that most committee members had no formal training in bioethics and no recent continuing education (8).

PROBLEMS BEYOND THE SCOPE OF AN ETHICS CONSULTATION

In some cases the problems concern legal liability, staff conflicts, or discharge planning rather than strictly ethical issues. Nurses or house officers might want the ethics committee or consultant to resolve long-standing grievances. It is unwise for ethics committees and consultants to take on the duties of risk managers, hospital administrators, psychiatrists, or social workers.

PROCEDURES FOR ETHICS CASE CONSULTATIONS

For ethics case consultations to be generally accepted, they must be regarded as accessible and fair (3,7).

WHO CAN REQUEST ETHICS CASE CONSULTATIONS?

Attending physicians, who are responsible for patient management, clearly should have the power to ask for ethics consultations. Beyond that, patients or their surrogates, nurses, and house officers should also be able to request case consultations. Disagreements over the need for a consultation generally indicate serious conflicts over patient care or ethical issues. Restricting access to ethics consultations is likely to exacerbate such disputes; rather, to ensure fairness, both sides should be able to request a consultation. If someone other than the attending physician requests an ethics consultation, it is prudent for the ethics consultant to notify the attending physician.

WHO PARTICIPATES IN CASE CONSULTATIONS?

All persons directly involved in the patient's care should be invited to attend an ethics case consultation, such as the patient or surrogate, attending physicians, consultant, trainees, nurses, social workers, and other health care workers providing care. If the patient agrees, family members should also participate. Their attendance ensures that all pertinent information is presented and all viewpoints are represented. As a practical matter, people are more likely to accept recommendations if they are allowed to express their views and to hear the reasoning behind a decision. In some cases health care workers need to think through the ethical concerns before making recommendations to the patient or family. In such cases it is acceptable for the ethics consultants to meet with the health care team alone as a first step.

DOCUMENT RECOMMENDATIONS

Most consultants offer specific recommendations for resolving ethical dilemmas. For instance, in Case 16.1 the ethics consultation can recommend that more information about the patient's previous statements should be gathered and that clear and convincing advance directives should be respected.

Recommendations should be written in the medical record, together with their rationale. Unwritten recommendations invite misunderstandings and reduce accountability. Recommendations are more likely to be followed if they are brief and specific. Direct conversations with the team also increase acceptance of the recommendations.

As with any consultation, the attending physician retains the power to follow or not to follow the recommendations. Ethically and legally, that person, after receiving the recommendations, should act as a reasonable physician would.

ETHICS COMMITTEES AND ETHICS CONSULTANTS

Ethics consultations can be carried out in several ways, such as consultations by a full committee, a small team, or an individual consultant (9). These options have advantages and disadvantages, depending on the situation.

ETHICS COMMITTEES

Interdisciplinary ethics committees typically comprise physicians, nurses, house officers, social workers, and clergy. The committee should also include lay members, who often can point out overlooked issues and arguments and help health care workers better understand the patient's perspective.

The committee members' personal qualities are as important as their professional backgrounds. Colleagues should respect committee members for their clinical judgment and interpersonal skills. Committee members should be willing to learn about clinical ethics, receptive to different ideas and points of view, capable of dealing with emotionally charged topics and interpersonal disagreements, and able to tolerate ambiguity.

Advantages of Ethics Committees for Case Consultations

Diverse perspectives within an interdisciplinary committee can lead to thorough and thoughtful discussions (10), particularly in complex, difficult cases (11). An interdisciplinary ethics committee sends an important symbolic message to the hospital (10): Ethical issues are the business of everyone who cares for patients, and clinicians can learn to resolve ethical dilemmas. In addition, ethics committees can give a voice to the practical wisdom of experienced clinicians. Consideration by the full ethics committee might be particularly indicated if the case raises new or unusual issues, if the institution has no policy or an exception to the policy is being considered, or if the case has serious implications for the institution (9).

Disadvantages of Ethics Committees for Case Consultations

It might be difficult to mobilize a large ethics committee for urgent consultations. Also, decision-making power might be so diffused through a committee that no individual takes responsibility for a decision (12). Committee members might lack expertise and formal training in clinical ethics (8).

Ironically, a broadly representative committee might not raise diverse viewpoints because of group dynamics. Ethics committee members might feel pressured to reach consensus, avoid controversial issues, and downplay objections (3). The group might discourage members from considering fresh alternatives and seeking additional information. Such "groupthink" might lead to grave errors in judgment (13). Ethics committees might be especially vulnerable to groupthink because of demands for a timely recommendation despite uncertain information and conflicting values and interests.

INDIVIDUAL CONSULTANTS

Instead of an ethics committee, persons with special training in clinical ethics might conduct case consultations (14,15).

Advantages of Individual Consultants

Ethics consultants with special training might be more skilled at case consultation than committee members who have variable training in ethics and dispute resolution. Individual consultants might provide more timely consultation than committee members, obtain primary data, and provide follow-up.

Disadvantages of Individual Consultants

Undue deference to ethics experts. It might be difficult for others to challenge the recommendations of ethics "experts." As a result, discussion might be stifled and divergent viewpoints might not be considered.

Potential for individual bias. Practice standards and quality control are far less developed in clinical ethics than in medical subspecialties (16,17). Many persons carrying out ethics consultations might lack formal training in clinical ethics (8). Furthermore, ethics "experts" might disagree over recommendations in a specific case (18). An individual ethics consultant might provide idiosyncratic recommendations that most other recognized ethics consultants would reject. It would be misleading to represent a private belief or an opinion as the consensus of the field.

CONSULTATION TEAM

Ethics consultation might also be carried out by a small group of consultants, typically a subgroup of the full ethics committee. Such a team might be selected for their expertise and availability to provide ethics consultations.

In summary, ethics case consultations might help resolve ethical dilemmas. No single approach to ethics consultations is appropriate for all hospitals and situations (10,11). In some institutions there might be several individuals who are highly skilled at ethics consultations and are willing to carry them out. In other institutions no single person with special training or experience is available; in this situation a committee would be more sensible. Persons who conduct ethics case consultations need to be aware of the potential pitfalls and the steps that can be taken to avoid them.

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CHAPTER 17

Do Not Attempt Resuscitation Orders

Everyone who dies suffers a cardiopulmonary arrest. Although cardiopulmonary resuscitation (CPR) might revive some patients after cardiopulmonary arrests, in severe illness CPR is much more likely to prolong dying than to reverse death. This chapter discusses the effectiveness of CPR, appropriate reasons for Do Not Attempt Resuscitation (DNAR) orders, the interpretation of such orders, and discussions with patients or surrogates about CPR.

CPR differs from other medical interventions in several ways. When a cardiopulmonary arrest occurs, physicians or nurses who might not know the patient must decide immediately whether to initiate CPR. Otherwise the patient will certainly die. Thus, CPR is attempted in every patient who suffers a cardiopulmonary arrest unless a prior decision has been made not to do so. Unlike other medical interventions, CPR is initiated without a physician's order. Instead, a physician's order is required to withhold CPR—the DNAR order or the No CPR order.

THE EFFECTIVENESS OF CPR

To make informed decisions about CPR, patients (or their surrogates) need to understand the limited effectiveness of CPR in many clinical situations. When CPR is attempted on general wards of an acute care hospital, circulation and breathing are restored in about 40% of cases (1). Of those initially resuscitated, about one third survive to discharge from the hospital. Thus, about 14% of patients on whom CPR is attempted are discharged alive from the hospital (1,2). In other words, even when CPR is attempted, about 86% of patients die. CPR is more effective when patients suffer cardiopulmonary arrests in the operating room, the cardiac catheterization laboratory, and intensive care units (ICUs).

In certain patient groups CPR is even less beneficial. Survival to discharge is significantly lower in patients with metastatic cancer, sepsis, and elevated serum creatinine (1). For patients with metastatic cancer, several older series reported zero survival after CPR (3), although two more recent series report about 10% survival rates in such patients (4,5). In the most recent series, there were no survivors if the arrest was anticipated and occurred after the patient gradually deteriorated, but 22% of patients with unexpected cardiopulmonary arrest were successfully resuscitated and survived to discharge (6).

For patients with sepsis, survival is also highly unlikely. In one series only 1 of 73 patients survived, whereas in another study 0 of 42 patients survived (7,8). CPR is usually ineffective in the elderly, but it is not clear whether this is due to age *per se* or comorbid diseases in the elderly (1,7,9). Outcomes for nursing home residents who receive CPR are also poor. In two series, 0% and 1.7% of nursing home residents on whom paramedics attempted CPR survived (10,11).

Complications might occur in patients who are revived by CPR. A dreaded outcome of CPR is severe neurological impairment. Even though circulation is restored, the brain might suffer severe anoxic damage. In one series only 1 patient survived to discharge among 52 patients who remained

unconscious 24 hours after successful initial resuscitation (12). Other medical complications might also occur during CPR. For example, fractured ribs or sternum or flail chest occur in 30% of cases (13).

JUSTIFICATIONS FOR DNAR ORDERS

As with other medical interventions, there are several acceptable justifications for withholding CPR.

PATIENT REFUSES CPR

Competent, informed patients might not want CPR. Many patients wish to die peacefully rather than have physicians and nurses attempt to revive them. Such informed refusals should be respected (14). However, in a large study, when patients wanted CPR withheld, a DNAR order was written in only about 50% of cases (15).

SURROGATE REFUSES CPR

Surrogates might decline CPR for patients who lack decision-making capacity (14). Surrogate decisions should be based on the patient's preferences or best interests.

CPR IS FUTILE IN A STRICT SENSE

As Chapter 10 discusses, physicians may decide unilaterally to withhold interventions that are futile in a strict sense.

CPR Has No Pathophysiological Rationale

A patient might be obviously dead for a length of time incompatible with successful resuscitation. For example, a patient might have rigor mortis or dependent lividity.

Cardiac Arrest Occurs Despite Maximal Treatment

For example, a patient might have progressive hypotension despite maximal therapy.

CPR Has Already Failed in a Patient

When a patient remains pulseless after resuscitative efforts by paramedics in the field, continued CPR would be futile (14).

In these strictly defined situations, physicians appropriately make the decision to stop or withhold resuscitation and CPR should not be offered to patients or surrogates (14,16,17). Instead, physicians should inform them of the DNAR order or the termination of CPR and explain the reasons.

Problematic Appeals to Futility

Physicians often use futility in a looser sense to justify unilateral decisions by physicians to withhold CPR.

Survival after CPR is highly unlikely. Some physicians assert that CPR is "futile" when patients are highly likely to die even if CPR is attempted.

CASE 17.1 Family wants CPR even though survival would be highly unlikely.

A 54-year-old man, bedridden with squamous cell carcinoma of the lung metastatic to liver and bone, is hospitalized for pneumonia. He has never indicated his preferences about CPR. The family insists that he be a "full code," saying that even if he does not regain consciousness or survive the hospitalization, it is worth prolonging life for even a few hours or days. The physicians, however, consider CPR futile because the medical literature reports that very few such patients are discharged alive after cardiopulmonary arrest (3). Furthermore, the doctors consider his quality of life extremely poor.

In Case 17.1 the family regards the goal of CPR as prolonging life, even if it would be unprecedented for the patient to be discharged alive from the hospital. Most physicians, however, consider the goal of CPR to be patient survival to hospital discharge, not merely temporary restoration of

circulation and breathing. They point out that society and the medical profession are not obligated to do everything that a patient requests (18,19). Prolonging the patient's life for a few hours or days is not an appropriate goal for care (17).

However, unilateral DNAR orders based on low likelihood of success are problematic (*see* Chapter 9) (20). First, rigorous data outcomes exist for very few clinical conditions (21). Second, physicians are inaccurate and unreliable in predicting outcomes of CPR. One study found that physicians were no better at identifying patients who would survive resuscitation than would be expected by chance alone (1). Third, physicians often define futility far more broadly than recommended in the literature. In a study of DNAR orders based on a quantitative definition of futility, in 32% of cases residents estimated the patient's probability of survival after CPR to be 5% or higher (22). This definition is far looser than the criteria for futility proposed in the literature—namely zero successes in the previous 100 cases (18,19).

The patient's quality of life is unacceptable. Some physicians and ethicists claim that CPR may be withheld from patients who are in a persistent vegetative state or who cannot survive outside an ICU (18,19). As discussed in Chapter 9, it is problematic for physicians to judge that the patient's quality of life is so poor that interventions are futile. DNAR decisions based on such a qualitative notion of futility are also suspect because physicians who make such judgments about competent patients commonly do not talk to them about their quality of life (22).

DISCUSSING DNAR ORDERS WITH PATIENTS

Patients or surrogates need to discuss CPR with physicians if they are to make informed decisions about it. Physicians cannot accurately determine patients' preferences about CPR without asking them directly. In the large multicenter SUPPORT study, physicians misunderstood patients' preferences about CPR in about 50% of cases (23).

BARRIERS TO DISCUSSIONS

Some physicians believe that patients do not want to discuss DNAR decisions. In fact, most ambulatory patients—between 67% and 85%—want to discuss life-sustaining treatment with physicians (24,25). Among hospitalized patients, between 42% and 81% want to discuss end-of-life decisions with their physicians (26,27).

Physicians sometimes hesitate to discuss DNAR orders with patients, fearing that they will lose hope, become depressed, refuse highly beneficial treatments, or even attempt suicide. Such adverse outcomes, however, almost never occur.

TARGETING DISCUSSIONS

Physicians typically discuss CPR only with patients whom they believe are at high risk for cardiopulmonary arrest. The prospect of cardiopulmonary arrest becomes more salient as a patient's condition worsens. However, if discussions are deferred, patients might become so sick that they are no longer capable of making medical decisions on discussing CPR with their physicians (28). Additionally, targeting sicker patients for discussions about CPR reinforces the belief that DNAR discussions signify a bleak prognosis. Selective discussions might also be inequitable. Physicians discuss DNAR orders more frequently with patients with acquired immunodeficiency syndrome or cancer than with patients with cirrhosis, who have similarly poor prognoses (29).

For these reasons physicians should routinely discuss CPR with all adult inpatients with serious illness. Ideally, such discussions would be initiated in the ambulatory setting. When patients lack decision-making capacity, physicians should conduct discussions about CPR with appropriate surrogates.

PATIENT MISUNDERSTANDINGS ABOUT CPR

Many patients misunderstand basic information about the nature of CPR. Few patients understand that mechanical ventilation is usually required after CPR and that patients on a ventilator are usually conscious but cannot talk (30). Patients substantially overestimate favorable outcomes after

CPR (31). Many patients who initially accept CPR change their minds after they are informed about the nature and outcomes of CPR (31,32).

IMPROVING DISCUSSIONS ABOUT DNAR ORDERS

Better discussions with physicians will help patients make informed decisions. Table 17-1 summarizes the following suggestions.

Place Discussions in Context

It is often better to start with a discussion of the patient's concerns and goals for care rather than the specific decision about CPR (33).

Routinely Invite Patients to Discuss CPR

Physicians can raise the issue of CPR in a straightforward manner. "I try to discuss with all patients what to do if they become too sick to talk with me directly. How would you feel about discussing this?" If the patient agrees, the physician can continue, "One important issue is CPR. Let me explain what CPR is . . . " Some physicians try to dissuade patients from CPR by describing it in graphic detail, such as "pounding on your chest." Such biased information, however, undermines the goal of informed patient decision-making.

Provide Information so that Patients Can Make Informed Decisions

Often, doctors shroud DNAR discussions in euphemisms or technical jargon (34). Physicians sometimes ask patients, "If your heart or lungs stop, would you like us to start them up again?" Such phrasing suggests that CPR is as simple and effective as jump-starting an automobile battery or changing an electrical fuse. The question is whether patients want doctors to *try* to revive them, even though the likelihood of death is 86% or more. Physicians can be explicit without being blunt or offensive. To avoid bias due to framing effects, physicians should explain that if CPR is attempted, overall 14% of patients will survive the hospitalization and 86% will die. Doctors can describe CPR (including chest compressions, electroshock, and intubation) and the possible outcomes (including survival, persistent unconsciousness, and death). Even after discussions with physicians, patients often have serious misunderstandings about CPR. For example, patients often do not realize that after resuscitation, mechanical ventilation is usually needed (30).

Make Explicit Recommendations About CPR

Physicians can offer recommendations while still allowing patients ultimate decision-making power. If CPR would be futile in a strict sense, physicians should not offer patients or surrogates a choice but instead inform them of the DNAR order and its rationale.

Reassure Patients About Ongoing Care

Some patients fear that after a DNAR order, physicians will give up on them. Physicians need to emphasize plans for treating other problems, seeing the patient regularly, and providing palliative care.

TABLE 17-1

Improving Discussions with Patients or Surrogates about DNAR Orders

Routinely invite patients to discuss CPR.
Provide information so that patients can make informed decisions.
Make explicit recommendations about CPR.
Reassure patients about ongoing care.
Repeat discussions at subsequent visits.

Repeat discussions at subsequent visits

Patients or surrogates often need time to think about issues and deal with their emotions. Thus, repeating discussions helps them make informed choices about CPR.

Physicians can improve their skills at DNAR discussions. Currently, doctors seldom observe more experienced physicians carry out such discussions or have colleagues watch them (35). Asking the advice of colleagues about a particular situation, role playing, and reviewing videotapes of simulated discussions might be helpful.

IMPLEMENTING DNAR ORDERS

WRITING A DNAR ORDER

DNAR orders are common in critically and terminally ill patients. CPR is not attempted for 89% of seriously ill patients who die in acute care hospitals (36). To prevent misunderstandings, physicians should write DNAR orders in the medical record. In addition, the physician should explain in a progress note the rationale for the DNAR order, document the agreement of the patient or surrogate, and describe plans for further care. In an urgent situation, nurses may accept a DNAR order over the telephone, with the understanding that the physician will sign the order promptly. DNAR orders should be reviewed periodically, particularly if the patient's condition changes.

Oral DNAR orders might lead to mistakes, misunderstandings, and confusion. They create ethical quandaries and legal jeopardy for nurses who respond to cardiopulmonary arrests. Generally, the use of oral rather than written DNAR orders indicates serious disagreements and a need for further discussions.

INTERPRETATION OF DNAR ORDERS

Implications for Other Treatments

Strictly speaking, a DNAR order means only to withhold CPR. Other treatments, such as antibiotics, transfusions, and even intensive care, might still be appropriate. However, the same reasons that make CPR inappropriate might also render other interventions unsuitable. Many hospitals now require more detailed orders than simply "no CPR." For example, the physician might have to specify on a checklist whether to provide mechanical ventilation (37,38). Such detailed orders are useful because nurses need to know whether abnormalities such as hypotension or ventricular arrhythmia should be treated or allowed to progress and lead to cardiopulmonary arrest.

"Limited" or "Partial" DNAR Orders

In some cases physicians may wish to restrict resuscitative efforts to a fixed period or withhold aspects of advanced life support, such as defibrillation or intubation (7). One rationale for physician-limited DNAR orders is that patients who do not respond to basic CPR might have suffered irreversible brain damage. The fear is that resuscitation might restore breathing and circulation in a patient who will never regain consciousness. However, this rationale is problematic. During an attempted resuscitation, there are virtually no reliable signs of irreversible brain damage or brain death (14). Furthermore, stopping resuscitation after basic CPR will reduce the chances for patient recovery. Even if basic CPR is ineffective, advanced life support might restore circulation, breathing, and consciousness.

"Limited" DNAR orders are appropriate, however, when an informed patient (or surrogate) consents to them or requests them. For instance, patients with chronic obstructive lung disease may decline mechanical ventilation but agree to other resuscitative measures.

Preventing Misunderstandings

Some physicians are reluctant to write DNAR orders because they fear that other health care workers—consultants, house staff, nurses, or respiratory therapists—might cease to provide needed care to the patient. Conversely, some nurses believe that once a DNAR order is made, physicians will stop rounding on patients or stop talking to them. Concerns that DNAR orders might lead to suboptimal care need to be addressed openly. Everyone needs to appreciate that DNAR orders do not mean "provide no care."

Slow or Show Codes

"Slow codes" or "show codes" appear to provide CPR but actually do not—or do so in a way that is known to be ineffective (39,40). For example, the code team is not paged immediately, a medical student is allowed to make repeated attempts to intubate the patient, or drugs are injected into the bed rather than into the patient. Such orders are usually given orally and not written down. Slow or show codes are commonly considered when the patient has a grim prognosis but an attending physician insists that CPR be attempted or the patient or surrogate insists that "everything" be done. Show codes are unacceptable because they deceive patients or families, compromise the ethical integrity of health care professionals, and cause confusion and cynicism among health care workers.

SPECIAL SETTINGS

Anesthesia for Surgery and Invasive Procedures

Patients with DNAR orders might undergo surgery for palliation or conditions unrelated to their primary diagnosis (41). Many physicians want to "suspend" DNAR orders in the operating room, when the patient's vital functions are deliberately depressed by anesthesia and maintained using techniques similar to those of advanced cardiac life support (42–44). If resuscitation were not permitted, medications might be titrated to ensure greater hemodynamic stability but lighter anesthesia, less analgesia, and less amnesia. CPR is much more successful in the operating room than elsewhere in the hospital. In one study, 65% of patients who had a cardiopulmonary arrest in the operating room survived to discharge and 92% of those whose arrest was caused by anesthesia survived (45). Another reason for suspending DNAR orders during surgery is the physician's sense of responsibility for intraoperative deaths (*see* Chapter 38).

If patients with DNAR orders undergo surgery or invasive procedures, physicians should discuss how the DNAR orders will be interpreted perioperatively (41). Plans should be documented clearly in the medical record. Similar considerations apply to DNAR orders in radiology departments, where medications might lead to cardiopulmonary arrest that is easily reversed (46–48).

Emergency Medical Services

When emergency medical personnel are called to the home of a patient with serious illness, CPR might not be appropriate. Paramedic policies and protocols should include provisions for DNAR orders (14). DNAR orders can be documented with an identification card or bracelet, a sticker on the telephone or refrigerator, a formal order sheet, or a computerized registry. A DNAR order should not preclude other appropriate care, such as oxygen or transport to the hospital. Similarly, emergency departments need to establish DNAR policies and procedures.

Nursing Homes

Few nursing home residents who suffer cardiopulmonary arrest are successfully resuscitated (10,11). Extended care facilities should establish institutional policies about the provision of CPR and procedures for designating residents as not to be resuscitated. Residents with DNAR orders should have access to appropriate emergency services.

Family Presence During Resuscitation Efforts

Many family members would like to be present during resuscitation efforts (14,49). Studies show that the overwhelming majority of relatives who observe resuscitation attempts view it as important and helpful. Being present might also help them adjust to the patient's death and reduce the likelihood of prolonged grief. In contrast, many physicians and nurses object to relatives being present during resuscitation, fearing that it will prove traumatic for laypeople, cause stress in caregivers, or even interfere with resuscitative attempts. Because family members apparently find that the benefits of their presence outweigh the risks, hospitals should offer relatives the opportunity to be present at resuscitation efforts (14). Hospitals should prepare the family for what they will see and provide emotional support.

In conclusion, CPR is not appropriate for many patients. Physicians should elicit patients' preferences about CPR and write DNAR orders in the medical record. For physicians the question is no longer whether they should discuss DNAR orders with their patients but how to do so with compassion and caring.